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DOI:

[10.1007/s00127-016-1257-9](https://doi.org/10.1007/s00127-016-1257-9)

Document Version

Peer reviewed version

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Citation for published version (APA):

Wallace, G., Bird, V., Leamy, M., Bacon, F., Le Bouillier, C., Janosik, M., MacPherson, R., Williams, J., & Slade, M. (2016). Service user experiences of REFOCUS: a process evaluation of a pro-recovery complex intervention. *Social Psychiatry and Psychiatric Epidemiology*, 1-10. <https://doi.org/10.1007/s00127-016-1257-9>

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Title: Service user experiences of REFOCUS: a process evaluation of a pro-recovery complex intervention

Genevieve Wallace*

Research worker, King's College London, Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Victoria Bird**

Research Fellow, Wolfson Institute of Preventive Medicine, Queen Mary University of London, Newham centre for mental health, London E13 8SP,

*** Joint first authors**

Mary Leamy

Programme manager and trial coordinator, King's College London, Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Faye Bacon

Research worker, King's College London, Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Clair Le Boutillier

Research worker, King's College London, Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Monika Janosik

Research worker, King's College London, Health Service and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Rob Macpherson

Consultant psychiatrist, ²gether NHS Foundation Trust, Gloucestershire

Julie Williams

Research worker, King's College London, Health Service and Population Research Department,
Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London

Mike Slade

Professor of Mental Health Recovery and Social Inclusion, Institute of Mental Health, University of
Nottingham, Triumph Road, Nottingham NG7 2TU

+Corresponding author v.j.bird@qmul.ac.uk

Acknowledgments

This article presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research (PGfAR) Programme (Grant Reference Number RP-PG-0707-10040), and in relation to the NIHR Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and Institute of Psychiatry King's College London. The project will be published in full in the NIHR PGfAR journal. The views expressed in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the PGfAR programme or the Department of Health. Further information available at researchintorecovery.com/refocus

Word count 245 abstract, Overall 4523

Abstract

Purpose: Policy is increasingly focused on implementing a recovery-orientation within mental health services, yet the subjective experience of individuals receiving a pro-recovery intervention is understudied. The aim of this study was to explore the service user experience of receiving a complex, pro-recovery intervention (REFOCUS), which aimed to encourage the use of recovery-supporting tools and support recovery-promoting relationships.

Methods: Interviews (n=24) and two focus groups (n=13) were conducted as part of a process evaluation and included purposive sample of service users who received the complex, pro-recovery intervention within the REFOCUS randomised controlled trial (ISRCTN02507940). Thematic analysis was used to analyse the data.

Results: Participants reported that the intervention supported the development of an open and collaborative relationship with staff, with new conversations around values, strengths and goals. This was experienced as hope-inspiring and empowering. However, others described how the recovery tools were used without context, meaning participants were unclear of their purpose and did not see their benefit. During the interviews, some individuals struggled to report any new tasks or conversations occurring during the intervention.

Conclusion: Recovery-supporting tools can support the development of a recovery-promoting relationship, which can contribute to positive outcomes for individuals. The tools should be used, in a collaborative and flexible manner. Information exchanged around values, strengths and goals should be used in care-planning. As some service users struggled to report their experience of the intervention, alternative evaluation approaches need to be considered if the service user experience is to be fully captured.

Declarations of conflicting interest: None

Key words: Recovery, health service and population research, process evaluation, complex intervention

Introduction

Personal recovery has been defined as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness” [1]. A systematic review and narrative synthesis identified five key recovery processes: Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment[2].

Recovery underpins national mental health policy in many Anglophone countries, highlighting an intention to move away from directive services with a narrow focus on symptom reduction [3,4]. Despite emerging clarity around the meaning of recovery [2,5] and prioritisation within mental health service policy, delivery of a recovery-orientation within routine practice remains challenging [6,7,8]. Concerns have been raised about the mainstreaming of recovery within services [9], and how risk management can be successfully balanced within a recovery-promoting service aiming to minimise coercion [10]. Despite studies focussing on the service user experience of care [11,12], or the overall meaning of recovery [13], less evaluative work has been conducted into the experience of receiving a pro-recovery intervention or service.

The REFOCUS programme was a 5-year research programme aiming to improve the recovery-orientation of community mental health teams in England through the development and testing of a manualised team-based complex, pro-recovery intervention [14]. The intervention and evaluation were based on best practice in recovery support, and systematic reviews of personal recovery [2], strengths [15], recovery measures [16] and recovery support measures [17]. The REFOCUS intervention was evaluated within a cluster randomised controlled trial [18].

In line with best practice trial methodology [19], a process evaluation, aiming to understand the experience of individuals receiving and delivering the REFOCUS intervention, was undertaken as part of the RCT. This paper focuses on the service user experience of receiving the intervention, and aims to provide ecologically valid evidence about the impact of recovery-orientated care on the experience of service users.

Method

As part of the REFOCUS process evaluation, semi-structured individual interviews and focus groups were conducted with service users who received care from teams in the intervention arm of the trial.

Refocus intervention and trial

The REFOCUS Trial (ISRCTN02507940) took place across adult community mental health teams in two Trusts in England: South London and Maudsley NHS Foundation Trust (SLaM) and 2gether NHS Foundation Trust (2gether) in Gloucestershire. The trial evaluated a one year manualised, pro-recovery intervention, delivered to whole community mental health teams. The intervention was intended to be integrated into routine clinical practice, and consisted of two components: pro-recovery Working Practices and Recovery-promoting relationships. The Working Practices (WPs) provided staff with materials to support: Understanding values and treatment preferences (WP1), Assessing strengths (WP2), and Supporting goal-striving (WP3), and were designed to be used collaboratively with service users. Staff were not required to explicitly reference the REFOCUS intervention when using the WPs.. The WPs were provided in the context of Component two: Recovery-promoting relationships. Teams were supported to develop a shared understanding of the meaning of personal recovery, as well as recognise service users as equal partners in their care. Attitude and value change was promoted through personal recovery training and a coaching skills-based training course. Recovery promoting relationships were also promoted through supporting teams to initiate a 'partnership project' which encouraged staff and service users to work collaboratively on a shared task or activity of their choosing.

Twenty-seven community mental health teams from SLaM (18 teams) and 2gether (9 teams) participated in the trial. Teams were eligible for inclusion if they provided a care co-ordinating function for service users. Fourteen teams (nine in SLaM, five in 2gether) were allocated to the intervention with the remaining teams allocated to standard care. The 14 intervention teams comprised recovery (n=9), psychosis (n=2), forensic (n=2) and low support teams (n=1). Although the name and client group of teams varied, they all aimed to support the recovery of individuals with mental health difficulties in the community.

Ethical approval

The study was approved by East London Research Ethics Committee (Ref. 11/LO/0083) on 22/2/11.

Participants

For the individual interviews a purposive sample of 24 individuals was recruited from 11 of the 14 intervention teams. The sample aimed to maximise variation in trial site, service location, time in mental health services and diagnosis. To be included, service users were required to meet the following criteria a) received the REFOCUS intervention based on staff or self-report during the previous 12 months, b) well enough to take part as decided by their care coordinator and c) could speak and understand English.

Focus groups were conducted with a convenience sample of individuals who had taken part in two partnership projects: the 'Let's Be Well' website and 'Outward Bound' activity day, in which staff and service users worked together to create a website highlighting local resources, and embarked on a range of outdoor adventure activities, respectively. These were chosen as they represented both sites of the trial and were contrasting project.

Procedure

A semi-structured interview schedule was developed in collaboration with the REFOCUS Lived Experience Advisory Panel (LEAP) - a group of individuals with personal or family experience of mental health difficulties, who provided Patient Public Involvement to the programme. The schedule aimed to gather in-depth data relating to the experience of receiving the REFOCUS intervention and included questions on the experience of services in the last year, recovery promoting relationships and the WPs. The focus group topic guide covered the experience of participating in a partnership project and aimed to capture the shared experience of these group-based projects.

Snowballing and networking techniques identified service users for the interviews. Staff members were asked to identify individuals with whom they had used the intervention over the year. Additionally, where service users reported experiencing elements of the intervention during the trial outcome evaluation interviews (conducted at 12 months post randomisation), they were invited to participate. Data collection and analysis was concurrent, with recruitment continuing until category saturation was reached. Interviews were conducted between 6 and 14 months post-randomisation to give individuals sufficient time to experience the intervention. The focus groups were conducted at the end of the trial after outcome assessment.

Prior to the interview and focus groups, participants were provided with information about the study, written informed consent was obtained, and socio-demographic information collected. The interviewers were all from professional research backgrounds, had in-depth knowledge of the

intervention, and received training in conducting interviews from members of LEAP. Each focus group was facilitated by two researchers. The interviews lasted between 35 and 65 minutes, with both focus groups lasting approximately 90 minutes.

At the end of each interview or focus group, participants were given the opportunity to ask questions and reflect on their experience. Individuals received remuneration for their participation (£20 for focus groups, £10 for interviews). The research was conducted at local community mental health team bases or in the participant's home. Following data collection, interviewers recorded their initial impressions and identified emergent themes in memos which were used during data analysis [20].

Data analysis

Interviews and focus groups were recorded, transcribed verbatim and anonymised. Transcripts were coded using NVivo qualitative data analysis software version 8. Thematic analysis was used for the data analysis following the guidance of Braun and Clarke [20]. Initially, the first four interview transcripts were coded inductively by three independent coders (VB, FB and MJ) to identify pertinent codes within the text. The coders met to discuss the codes and develop an initial coding framework. The interview schedule was modified to reflect emerging codes with data collection continuing concurrently with the analysis. Two researchers (VB and GW), including one researcher with a professional/service user background, independently applied the coding framework to the remaining transcripts. The coders met regularly to iteratively update and modify the coding framework, and any differences in coding were discussed with alternative interpretations of the data recorded as memos. The two researchers reviewed and refined the codes, seeking to organise them into overarching themes. For each of the themes and sub-themes a definition was created. The language of the original data extracts was used to inform their headings and definitions.

Results

Twenty-four service users participated in individual interviews; 17 from SLaM and 7 from 2gether (TGT). A further six participants (from a range of teams across both Trusts) declined to participate in the individual interviews. One focus group was conducted in each Trust and consisted of 6 and 7 service users respectively. Demographics of the participants are included in Table 1

INSERT TABLE 1 HERE

Themes were apparent across the individual interviews and focus groups, unless otherwise specified and were organised into three superordinate categories: 'Pro-recovery tasks and activities', 'The working relationship' and the 'Impact of the recovery intervention'. The first and second order categories are shown in Table 2.

INSERT TABLE 2 HERE

Category 1: Pro-recovery tasks and activities

Participants described their experience of the REFOCUS pro-recovery tasks and activities (Working Practices). These were three specific conversations and behaviours, which staff were encouraged to use with service users.

1.1 Understanding values and treatment preferences

Staff were encouraged to learn about the values and treatment preferences of individuals to inform care-planning, through conversational, narrative or visual mapping approaches. Participants reported new topics of conversation, particularly around sexuality and spirituality. This made participants feel that staff were 'genuinely' interested in them and wanted to get to know them as a person. As a result participants felt better understood, which helped to strengthen the working relationship.

'I just felt she is taking more interest in me, more than just coming and giving me injections, she wanted to know more about how I feel, what I'm doing, what I'm thinking.' (P3, M, SLaM)

Conversely other participants felt that asking questions about an area of life implied they had a problem in that area. In some cases, these individuals felt that the questions were intrusive, and did not want to discuss wider aspects of their life with staff.

'What I get up to and these things, they don't need to know, they just need to know what's important and if I'm behaving and that, I'm not straying and I'm taking my meds.' (P17, M, SLaM)

This highlighted the need for any recovery-orientated WPs to be delivered in an individualised way, such as only discussing areas important to the individual and ensuring conversations are service user-led.

1.2 Assessing strengths

The strengths assessment focussed on exploring the internal, external, service-related strengths and resources of individuals. When service users gave examples of their strengths they focused on

valued personal qualities such as resilience and kindness, and less on external strengths or resources. Participants reported having a greater awareness of their strengths following these discussions.

'It was good because it showed I've got a lot of courage, that's one of my strengths' (P11, M, SLaM)

Where individuals had difficulty identifying strengths, staff encouragement including highlighting the person's strengths were helpful strategies. Although only apparent in a few examples, discussions around strengths being taken further to include planning how to utilise those strengths, was seen as particularly useful.

'It makes me feel like it's something I can work with, something I can actually put into practice and make part of my routine. If I'm good at it and I want to do it, why shouldn't it?' (P2, M, SLaM)

1.3 Supporting goal-striving

Within any recovery-orientated service, staff are encouraged to learn about the personally-valued goals of people they support, work in partnership to support these goals, and use them to inform care-planning. Service users were more familiar with goal striving than the other pro-recovery tasks. Goals gave people a sense of direction and purpose in life, in essence something to '*aim for*'. Many participants gave examples of personal goals, and how these had been shared or discussed with staff.

'He'll ask me what else I want to do with my life, where I see myself in say a couple of years or something like that and in terms of set targets' (P13, M, SLaM)

Participants found it particularly useful when staff worked collaboratively with them on their goals, breaking them down into manageable steps, helping with motivation and identifying possible opportunities to aid goal-striving. Whilst achieving goals gave a sense of achievement, the process of setting goals, whether they were ultimately reached or not, was also seen as helpful and gave people a more positive outlook.

'It makes me realise that I could actually do something, it wasn't just pie in the sky, it did have a purpose.' (P23, F, TGT)

1.4 Reservations about the Working Practices

Some individuals could not recall having completed the WPs; for these individuals they were not memorable events. For others, the recovery activities and resources were not always positively experienced, particularly where they were delivered in a formulaic and generic way. In these cases, individuals saw them as another form to be completed for the benefit of staff.

'That fulfilled something for her more than it did for me y'know being asked "who's this" and "who's that", it didn't fulfil much for me (...) it was a sort of quick, a sort of bird pecking at the ground.' (P9, F, SLaM)

Participants highlighted that for discussions around strengths, goals and values to be useful, the information they gave should then be acted upon and incorporated into the care plan. Discussing and recording information without further action did not go far enough to support recovery.

'If you are just asking for asking's sake then there is nothing but if you use them and ask to see how they can better be suited to your mental your mental wellbeing, your care coordination, then yes.' (P3, M, SLaM)

1.5 Partnership project

As with any pro-recovery intervention or service, the aim of the partnership project was for staff members and service users to do something collaboratively and break down any 'them' and 'us' barriers. Participants from both focus groups described how the partnership projects gave opportunities for social interaction with other service users and staff. This led to new or stronger connections with others. Distinctions between service users and staff faded and relationships were as equals, in genuine partnership.

'There were times when I can truthfully say I couldn't distinguish between you know who were the punters if you like and who were the staff, and that's a good thing. (...) it was a different approach and probably a very good one.' (Focus Group, P1, M, TGT)

Some participants felt that the connections made during the project would continue to impact positively on their working relationship, with staff seen as *'more approachable'*. However, whilst many participants reported partnership working whilst taking part in the activity, it was clear that the organisation and management of the projects remained staff-led in most of cases. Service users described being *'invited'* to attend a pre-determined project, describing their involvement as *'consultation'* and their wish to be more comprehensively involved.

'We are going to an agenda that's already been set (...) it's definitely not our project.' (Focus Group, P3, M, SLaM)

Category 2: The working relationship

The working relationship was central to the intervention. The aim of the WPs was to facilitate a more recovery-focused working relationship built on collaboration and strengths-focused approaches.

2.1 Recovery-supporting changes in the relationship

Participants discussed how the REFOCUS intervention changed their relationship with staff by enabling staff to learn more about them. This was particularly linked to the Understanding values and treatment preferences WP, which gave individuals '*permission*' to discuss new topics, often neglected within traditional problem-focused conversations. This supported the development of a relationship in which service users felt staff were genuinely interested in getting to know them as individuals.

'She's looking at you know empowering me, which shows that she's interested in me as a person, I'm not just a statistic (...) she really cares. It really gives me a strong sense of our relationship; it has like I said improved markedly for that reason.' (P1, F, SLaM)

This helped to build mutual trust and respect in the relationship, with both parties '*warming*' to each other. Service users consequently felt more able to be open with staff. An increase in service user-directed conversations was also reported, with individuals feeling able to and wanting to contribute to the agenda of meetings.

'She's much more friendly. How can I say this, in a way I'm leading her places rather than she leading me' (P9, F, SLaM)

2.2 Pre-existing recovery-supporting relationships

Some participants described recovery-oriented features of a working relationship which could not be identified as an intervention-specific change; they predated the intervention. These relationships were characterised by involvement in decisions, goal setting, feeling listened to and respected as an individual, and were supported by the personality and personal values of staff.

'I've always felt involved really from beginning to end (...) they always kept me involved, kept me abreast of what's happening, asked my opinion and took it on board' (P6, M, SLaM)

In general, participants valued staff being supportive, '*genuinely*' caring, open and honest in a constructive but not dismissive way. Where relationships were already recovery-supporting, it is likely that any changes brought about by a specific pro-recovery intervention will be less distinct and harder for individuals to notice, especially where the intervention is integrated into routine care.

2.3 Lack of noticeable change in the relationship

There were also a number of participants who stated that their relationships with staff did not become more recovery-orientated during the REFOCUS intervention. They described decision-making power remaining with staff, with differences in opinion seen as evidence of pathology, and medication remaining the focus. Service users felt that some staff did not want the relationship or this power-dynamic to change.

'He just wasn't able to give up that element of control; he felt that if I got to that stage I needed to be in contact with them' (P22, F, 2gether)

A minority of participants also reported that they did not want their relationship with staff to change. This was particularly the case where individuals sought minimal involvement with services and were not receptive to broadening the role of services beyond risk and medication management. These participants often reported previous negative experiences of services, including forced medication and hospitalisation. In these cases, individuals could not imagine services being different.

'I don't think I've ever made a decision about my care, I don't know what kind of decision I would make about my care.' (P3, M, SLaM)

Category 3: Impact of the pro-recovery intervention

When participants were asked about the impact of REFOCUS, they often focused on specific activities or conversations. However, there was a large amount of overlap in the impact reported.

3.1 Empowerment

Individuals felt empowered by the intervention in relation to both their mental health and other areas of life. Being given increased independence and choice in their care indicated that staff believed they were capable of managing increased responsibility. This in turn made individuals feel more confident in their ability to cope.

'I found it quite liberating because you're asking me what I want, what I think is better for me... so I think it's given me a level of freedom and confidence because you feel that I can, I'm in a position where I can give you my opinion.' (P1, F, SLaM)

Some participants envisaged a future where they would feel less heavily dependent on staff and services. This was particularly apparent where participants had described working collaboratively with staff to achieve their goals.

'She's there for me, but I know in time I won't have to keep relying on this person.' (P19, F, 2gether)

3.2 Identity

Service users described how WPs used as part of the REFOCUS intervention facilitated greater self-awareness, prompting thoughts about a wide range of life areas that they otherwise rarely focused on, including their goals and values.

'When they asked these questions it makes you think about yourself in a different light, in a different way, about what you are doing and what you are thinking, how do you see yourself?' (P3, M, SLaM)

This self-knowledge included greater awareness of their strengths, valued personal qualities and available resources, which encouraged participants to have a more positive self-image. This was particularly attributed to the Strengths assessments, and was further enhanced by when staff took an interest in the strengths of the person.

3.3 Hope and optimism

Another important outcome for participants was an increase in hope. Participants across the interviews and focus groups described how this change was due to conversations focusing on strengths and successes both in the Assessing strengths WP and throughout the intervention. Staff members were encouraged to actively communicate their hope and belief in the person.

'I feel more positive that I can go for what I said I was going to go for, and if someone else believes in me then I more believe in myself.' (P13, M, SLaM)

Hope was seen by many participants as essential to recovery-promoting efforts, underpinning actions such as goal-striving or building relationships. Therefore increasing hope was felt to be very powerful.

'If you've lost hope then you've lost life (...) so it's good to have someone give you hope (...) that's the main thing, (...) she just lets me know that there's reason to have hope.' (P17, M, SLaM)

Discussion

Participants were able to describe components of the REFOCUS intervention and the impact these had on their recovery and working relationship with staff. When successfully implemented the intervention facilitated a mutually open and collaborative relationship between staff and service users. Participants were able to direct conversations and felt that staff got to know them as individuals. The intervention also led to a greater awareness of the person's strengths and values, leading to a more positive self-image, and increases in hope and empowerment. However, the intervention was not successfully implemented in all cases. Some participants experienced elements of the intervention in the absence of a recovery-promoting relationship. When delivered in this way, these elements were experienced as intrusive and for the benefit of staff. Finally, some individuals struggled to notice changes and could not describe any new tasks or conversations, thus questioning the implementation of the intervention.

The present study was conducted as part of a wider process evaluation nested within the REFOCUS RCT [21]. Within the RCT there were no group differences in recovery scores at the end of the intervention. However, the analysis indicated that where intervention teams had high levels of

participation, both staff and service user-rated recovery orientation scores were significantly greater than controls. The intervention also had positive effects on functioning and levels of unmet need, findings consistent with the present study. In particular, the WPs were seen as hope-inspiring and empowering, with a shift towards a strengths-focus and goals. Participants discussed how the intervention led to a greater awareness of their own strengths and resources; it is therefore possible that staff also gained more awareness of the strengths of the individual. A number of quantitative studies have assessed the effectiveness of recovery-focused interventions including recovery workbooks [22], Wellness Recovery Action Plans (WRAP) [23,24,25,26], peer-led education[27] and strengths-based case management [28] and also demonstrated increases in hope [24,27] and empowerment [22].

The overall lack of effect found in the RCT is consistent, in part, with the present analysis, which highlighted that for some participants, the changes brought about by the intervention were subtle, particularly when staff integrated the intervention into routine care. The findings suggest implementation issues including a lack of change in the relationships between staff and service users, and/or formulaic and non-individualised use of the recovery tools. This is consistent with the staff process evaluation, which specifically focused on the intervention implementation and highlighted barriers to implementation within routine practice, including organisational readiness and fit with routine targets and outcomes [29].

Strengths and Limitations

This is the first study to explore service user experiences of a team-level complex pro-recovery intervention. The use of a qualitative approach across two sites enabled an in-depth and nuanced understanding with increased generalisability. Many services are seeking to become more recovery-focused, and this study provides guidance on what service users do and do not find helpful in recovery-promoting relationships and recovery activities.

Despite this strength, the study had three limitations. Firstly, participants were selected based on self or staff reports of exposure to the REFOCUS intervention, so may not be representative of other service users. Secondly, the main interviewer (VB) helped to develop the intervention and all interviewers were known to be researching recovery, so social desirability bias may have led to over-reporting of change. Furthermore, as interviewers had knowledge of the intervention, individuals were prompted to aid recall of the different intervention components. Finally, asking participants to characterise interactions over the last 12 months may have led to recall bias.

Implications for practice

Three implications for practice were identified. Firstly, the tools provided to support the three WPs need to be seen as a means not an end. The WPs help build a recovery-promoting relationship and are of value when implemented within the context of a recovery-orientated relationship. However rigid and formulaic implementation was not helpful. Previous research indicates that staff tend to focus on particular tasks as evidence of 'doing' recovery thus, "omitting the underlying philosophy of recovery-orientated practice" [29,30].

Secondly, recovery-focussed tools should be integrated into care planning. Participants highlighted that conversations around values, strengths and goals needed to result in information being used to support their recovery. For example, goals need to be broken down into tangible steps, and available resources identified, including opportunities to use the person's strengths.

Thirdly, organisational transformation needs to balance technical skills (such as assessing strengths) with interpersonal qualities to promote power-balanced and hope-inspiring relationships. Service users described how being 'genuinely' caring and supportive, as well as honest and open in a constructive manner, were necessary staff qualities. [21]

Research implications

When asked about their experiences, some individuals were unable to recall the intervention, despite being identified by staff as having received it. Raising awareness of the intervention may help individuals identify subtle changes in the working relationship, and additionally may increase service user expectations of recovery-promoting practice from staff. One potential strategy for increasing awareness is to provide individuals with signals that the intervention is in use, such as the use of a handbook. This may also facilitate co-ownership of the intervention and promote increased collaboration.

Furthermore the intervention was intended to be integrated into practice and may have resulted in 'soft' changes to the working relationship. Where an intervention is integrated within routine care, evaluation from a service user perspective is challenging. Alternative approaches might include ethnographic investigations such as participant observation or the recording of interactions. Although not without their limitations [31,32], these may be more useful in detecting subtle changes.

This study is the first to expand upon the limited knowledge regarding the service user experience of a pro-recovery intervention. The findings highlight that when successfully implemented, the REFOCUS intervention supported the development of recovery-promoting relationships and contributed to recovery outcomes. However, the delivery of the intervention, including ineffective or inadequate implementation, was problematic. Finally, if research is to more adequately capture the experience of people using services, alternative evaluation approaches may need to be considered, particularly where interventions are embedded within routine care.

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